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ABSTRACT

This paper describes the development of a consumer-based program in rural Essex County (New York) for families with children with emotional disorders. Initially, in-depth, in-home interviews were held with 24 families who had children with serious emotional disturbances concerning their service needs and desires. The following needs were expressed by the families: respite, information and referral, an advocate, community friend/mentor for their child, support for caregivers, siblings, and the identified child; crisis services; concrete assistance; and family centeredness. The interviews led directly to development of 32 program recommendations in the development of the Families First in Essex County program. These included: preference for parents of children with special needs in hiring; inclusion of participants in all training as both attendees and trainers; no interagency meetings about families without their presence; a family's assertion that the child has emotional/behavioral problems and requires help as the only criterion for receiving services; and immediate service responsiveness (no waiting lists). The program has served 250 families in 39 months and an evaluation survey of consumers indicated a high degree of satisfaction. (DB)

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Families First in Essex County: A Family Designed and Implemented System of Care

Authors

Introduction Method Results Discussion

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Introduction

The goal of this project has been to develop a system of services for families with children with emotional disturbance that is designed and primarily implemented by consumers. From 1993 to 1996, the project was primarily funded by a Department of Health and Human Services Center for Mental Health Services research grant received by the New York State Office of Mental Health. The researchers will be presenting the research results at a future date. This summary presents a more subjective view by the founder and director of the program.

In the past ten years, the consumer movement has changed the face of service delivery, emphasizing the need for voice, ownership, and options for people receiving services, and an end to what our program refers to as "blame and shame." Value has been placed on families and professionals working in a partnership with the family in charge. Despite these values, even the best of systems have been primarily designed by professionals. The following are questions posed by this endeavor:

- What would a program look like that was developed in response to what families said they wanted and needed?
- Is it possible to develop a responsive system in an extremely rural area?

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Method

In 1991 several small grants were received to fund a planning year. In-depth, in-home interviews were held with 24 families who had children with serious emotional disturbance and tape recorded for subsequent analysis. The author asked each family the following questions:

- What was most helpful to you?
- What was not helpful to you?
- If you had a magic wand, what services would you wish for?

After the completion of the interviews, a Parent Planning Committee was formed, chaired by the project director. The committee's assignment was to make recommendations for a program based on the interview material. The committee met for eight two-hour sessions, which were videotaped. During the course of this planning year, an Essex County Child and Family Task Force was formed, which included service providers, community people, and consumers. The task force prioritized service system needs and were trained in Child and Adolescent Service System Program (CASSP) principles, with emphasis on family centered services. At each meeting, they heard a speaker who was a consumer tell the story about their experience as a service recipient.

Results

There was almost complete unanimity as to what families reported they needed and wanted. The following needs were expressed by the families interviewed: respite; information and referral; an advocate; community friend/mentor for their child; support for caregivers, siblings, and the identified child; crisis services; concrete assistance; and family center. When professionals design services for families, the services that were prioritized by families are usually developed years after other more traditional services, if at all.

The following is a sample of the 32 recommendations made by the Parent Planning Committee and implemented by Families First in Essex County: (a) Preference should be given to parents of children with special needs in hiring; (b) participants should be included in all trainings, as both attendees and trainers; (c) no interagency meetings should be held about families unless they are present (i.e., "Nothing About Me Without Me"); (d) there should not be any criteria for receiving services other than a family's assertion that their child has emotional/behavioral problems and they would like help; and (e) there should not be any waiting list (i.e., the program should be immediately responsive by providing support services).

More intensive services such as case management are not available to all referrals to Families First, but everyone who calls for assistance can utilize a variety of services. Families

calls for assistance can utilize a variety of services. Families may borrow books or videotapes from the Resource Library. They may call the 800 number for support from a parent/professional, or they drop in to the Center for support. Families are provided social events to attend. They can receive the family written newsletter and notices of events. Families may request an initial home visit for planning, or even ask to be matched with another participant for support. Also, they can receive food from the Families First food shelf and concrete help through the flexible dollar fund. Families have access to both respite for child care and the respitality program for an overnight stay in a hotel. Finally, they may have an opportunity to assist another family and/or contribute in other ways to the organization.

The Parent Planning Committee felt strongly that the language that professionals use can connote either respect or blame and shame. They recommended that the following terms be used: (a) "Multi-stressed" rather than "dysfunctional;" (b) "participant" rather than "client;" (c) "family" rather than "case;" (d) "family advocate" rather than "case manager;" and (e) "cautious" rather than "resistant."

The following summarizes the salient learnings from this demonstration project:

- If services meet people's needs, recognize their strengths, and are offered in a warm, hospitable and respectful environment, families will utilize the service. Even those who are usually the most difficult to engage (e.g., low socioeconomic families and mothers who are depressed), will participate.
- Traditional service providers are highly invested in maintaining the status quo and are likely to be very cautious about accepting a new paradigm of family centered service. Although significant changes were made in Essex County, such as having consumer representatives on interagency committees, it took three years before most other providers became comfortable with family centered values and procedures. Many continue to be very cautious.
- Hiring consumers is essential to a family centered service, but it presents many challenges. When staff both deliver and receive service, it requires great flexibility and sensitivity.
- Creating truly individualized, flexible services that incorporate the natural support system requires comfort with ambiguity and complexity, which can be an administrative and bookkeeping challenge.
- There is a tendency to revert to old paradigms. In order to assure that a program remains "family friendly," providers need to always be vigilant against slippage.

Discussion

Families First in Essex County opened its doors in

November, 1992. In 39 months, it has served 250 families, and the county has had fewer hospitalizations and out of home placements. An evaluation survey of consumers yielded a very high degree of satisfaction. Family members have said "Families First is my family," and "I have been lifted out of my depression since I joined the family of Families First." It has been clear that the agency has established a sense of community. The majority of participants assist other families, work in the office, help with social events or serve on the Board or on Advisory Committees.

The project has demonstrated that it is possible to develop a system of services that is designed and implemented by families, and that the resulting program will have services that actually please and delight recipients. It has also demonstrated that a system of family centered support services can function in a very rural area despite the challenges arising from lack of transportation, isolation, and a pool of trained professional people.

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